

414 The patient experience of cystic fibrosis clinical nurse specialists inserting peripheral longlines at the adult cystic fibrosis unit in Leeds

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Background: Of the 377 adult patients at the regional Cystic Fibrosis (CF) Unit, Leeds, 166 (44%) have Totally Implantable Vascular Access Devices (TIVAD). For the remaining 211 (56%) requiring intravenous antibiotic therapy, peripheral longlines are the preferred option for prolonged IV access. Following a reduction in medical cover (FY2) the CF Clinical Nurse Specialists (CNS) underwent training to extend their role and insert peripheral longlines. We aimed to compare the patient experience and complication rates following insertion by doctors or CNS.

Methods: CNS received formal training on longline insertion, and achieved practical competencies for this technique. An audit was completed over a 9 month period measuring patient satisfaction and associated complications in 9 key areas. Patient satisfaction was measured on a scale of 1–4 (1 = poor, 4 = excellent).

Results: 62 insertions were recorded (36 by doctors, 26 by CNS). There were no differences in patient satisfaction score [Median Patient satisfaction score was 3.5 (doctors) v 4.0 (CNS)], Mean Patency of longline was [10.8 days (doctors) v 10.2 days (CNS)], percentage insertions requiring more than 1 attempt [24% (doctor) v 19% (CNS)] or infection rates. Difference in waiting time to longline insertion was significant [40 min (doctor) vs 20 min (CNS); $p < 0.05$].

Conclusion: CNS achieved the same patient satisfaction scores and low complication rates as medical staff, whilst reducing waiting times. Extended CNS roles improve the patient experience.

416 'Someone to talk to': adolescent and adult CF patients' feedback on their experience of a mentoring and IT intervention

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Background: Equipping those affected by chronic disease with the skills needed to self-manage has been shown to improve both health-related outcomes and quality of life, but there has been little work in CF in this area. Adolescents and adults with CF participated in a randomised controlled pilot study that aimed to assist them to achieve increased levels of self-efficacy through interactions with volunteer mentors coupled with technology supported self-monitoring.

Method: Semi structured interviews (N=26) were used to complement the quality of life and clinical outcome measures utilised in this study, by giving participants the opportunity to feedback on all aspects of the intervention: the process, including the mentor relationship.

Results: Participants revealed general satisfaction, with an enhanced sense of personal accountability and symptom awareness being reported by those who had engaged successfully with the mentoring experience. Others offered constructive insight into factors affecting research participation, including the decision to do so, and 'working' the intervention. The appropriate deliverer of the mentoring – professional or volunteer – was also discussed.

Further candid unsolicited comments regarding usual care from clinic and carers provide invaluable feedback that is not always captured by questionnaire, but certainly warrants a hearing.

415 Improvement of care for patients with cystic fibrosis: introducing the electronic transmural patient dossier with home monitoring

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Introduction: The CF Center Utrecht is the largest CF Center in the Netherlands with about 230 children and 160 adult CF patients in care. The complexity of care has led to centralization of CF care. This resulted in an increasing need for consultation with the CF team.

Aim: To solve these problems we developed an electronic transmural patient dossier with patient-access (E-portal), connected to our Electronic Patient Dossier (EPD). The patient can access this portal with his own secure logincode.

Method: Through his personal E-portal, the patient has the opportunity to check part of his file at home. The E-portal includes access to:

- CF physician formulated treatment,
- current medication prescriptions,
- lab and microbiology results,
- lung function results,
- correspondence between caregivers,
- planning of outpatient visits.

The portal also offers possibilities for:

- e-consulting with the CF Nurse Practitioner,
- electronically renewing of prescriptions,
- entering home measured lung function,
- home sputum culture,
- preparing for hospital consultations through questionnaires on line.

The E-portal is a part of the site of the CF Center Utrecht (www.CF-Centrum.nl), where general information about the condition CF and the CF Center Utrecht can be found.

Results: The first patients received their personal login code on Jan 20th 2010. We aim to include 200 children before July 2010. The effects of the introduction of the E-portal on improving patient care will be studied extensively in the coming years. At this stage we would like to report about the aim and demonstrate content and implementation of the E-portal and the first experiences of the users (both patients and caregivers).

417 CF patients' experience of an adult ward following transition – an on-line survey

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Background: Transition from paediatric to adult care has become increasingly important as children with chronic illness survive into adulthood. Over half of the UK CF patients are adults.

Aim: Describe the experiences of ward admissions in young adults transitioned to an adult centre.

Methods: Consent was obtained from 90 patients who were sent an on-line questionnaire. Areas asked about included experiences of transition, healthcare staff and the ward services and environment.

Results: The response rate was 78% (n=70) and mean age was 20.3 yrs (range 16–24 yrs). 83% of participants had attended a transition clinic (n=58). 91% (n=53) would have chosen to attend a transition clinic if given the option again ($p < 0.0001$). Of those who had not previously attended ten said they would if asked now. Participants who had been in the adult centre for >5 yrs (23%) rated their admission experiences higher than those who had joined the centre more recently ($p < 0.03$). The CF Team were scored more highly than ward based staff ($p < 0.1$).

Discussion: Response rate may reflect the use of an on-line questionnaire in this younger population. The majority of participants had attended a transition clinic and acknowledge its usefulness. Those who had been attending the adult centre for longer were happier with all aspects of an admission. CF Team Members with specific training and experience of this age group received higher scores than the ward based staff.

Conclusion: The importance of transition clinic and support that patients receive from the CF team is acknowledged. While patient experience scores improve with time, there is a clear need to improve support and education for ward based staff.